



APPROVED - 10/08/13

**MINUTES OF THE SEPTEMBER 10, 2013 MEETING OF THE PATIENT
CONSENT PREFERENCES & DATA SECURITY WORKGROUP OF THE ILLINOIS HEALTH INFORMATION
EXCHANGE AUTHORITY BOARD**

The Patient Consent Preferences & Data Security Workgroup (Workgroup) of the Illinois Health Information Exchange (ILHIE), pursuant to notice duly given, held a meeting on September 10, 2013, at the offices of the Illinois Health Information Exchange (ILHIE), State of Illinois James R. Thompson Center, Room 2-201, 100 W. Randolph St., Chicago, IL 60601; with telephone conference call capabilities.

<u>Members Present:</u> Peter Eckart (Co-Chair), Illinois Public Health Institute Harry Rhodes (Co-Chair), American Health Information Management Association Deb Gory , Metropolitan Chicago Healthcare Council Victor Boike , Metro Chicago HIE Glenn Susz , APP Design Sarah Koenig , APP Design Joy Duling , Central Illinois Health Information Exchange Colleen Connell , American Civil Liberties Union Lawrence Johnson , iCare Health Informatics Neil Marcus , Marcus Law Howard Lee , Wirehead Technology	<u>Members Present by Phone:</u> Amanda Attaway , Illinois State Medical Society Patricia Joseph , Prospects Information Morris Rang , Blessing Hospital Jud Deloss , Popovits & Robinson Satyender Goel , Chicago Health Information Exchange Regional Extension Center Nick Bonvino , Southern Illinois Healthcare Chris Freeman , Pillars Community Services Mikki Pierce , Atrium Advisory Services Carl Gunter , SHARPS
<u>OHIT Staff Present:</u> Raul Recarey , ILHIE Ivan Handler , ILHIE Krysta Heaney , OHIT Ola Oni-Fatoki , ILHIE (by phone) John Lekich , ILHIE (by phone) Kerri McBride , ILHIE Beth LaRocca , OHIT Daniel Procyk , OHIT Lindsay Friedman , OHIT	

Call to Order and Introductions

Ms. Kerri McBride confirmed the presence of the members and welcomed the participants to the Workgroup. Ms. McBride facilitated brief introductions, confirmed the ability of the Work Group Members participating by telephone to hear the proceedings, and called the meeting to order at 2:00

pm. Mr. Peter Eckart and Mr. Harry Rhodes expressed their optimism and proceeded with a general meeting introduction and overview of the agenda.

Discussion

Mr. Handler stated that next June, the group would be making a recommendation to the ILHIE Authority about next steps in terms of patient preferences and data security. Consequently, although he expected the recommendation to come from the entire group, he neither expected nor required consensus on all issues.

Mr. Eckart reviewed the 5 tasks that were sent in advance of the meeting. They were as follows:

- 1) Gather the concerns of Illinois patients, including previously collected concerns and updates from stakeholders,
- 2) Develop “personas” (like-use cases) to represent those concerns,
- 3) Request technical presentations which respond to the personas,
- 4) Evaluate potential solutions for relevancy and feasibility, and
- 5) Make recommendations to the ILHIE Authority Board.

Ms. Deb Gory asked a question about the extent and scope of the Workgroup’s objective. Mr. Handler clarified that the Workgroup was attempting to operationalize patient consent preferences and data security, and that the objective of the Workgroup was primarily operational, rather than regulatory in nature.

It was emphasized that although some of the technology is not currently available to accommodate health information data segmentation, a lack of technical means should not detract from moving forward with potential policy considerations and solutions to various issues identified by the Workgroup. Taking this approach is important both internally, for the purposes planning for the future, as well as externally, in terms of influencing the national stage.

Workgroup members noted that younger individuals and patients with complex medical histories were perceived to be more receptive to freely exchange health information than middle aged individuals. Likewise, it was pointed out that recent events regarding widespread technological data breaches have had a negative effect on the public’s view of data privacy and security. As such, the need for a multifaceted solution was affirmed. It was noted that this type of solution involved balancing the goal of attaining a private and secure ILHIE with the goal of effective and efficient health care.

To aid in advancing the Workgroup’s goals and to help identify specific patient concerns, it was stated that one or more hypothetical “personas” would provide the best means to examine various scenarios. This was particularly well received by experienced practitioners who were less versed in the technological aspects of consent preferences and data security.

Review of Timeline

A monthly meeting schedule was agreed upon.



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Mr. Eckart and the group reviewed the timeline, working backward from the date of the Workgroup's presentation to the Board's i 2014 summer meeting. By next summer, the Workgroup is expected to have a finished report that will be "signed off" by the Workgroup. By May, all work for the report should be finished and a draft version of the report will be circulated. Prior to May, the Workgroup will develop the first four tasks by creating four or five personas and by taking a closer look at data segmentation technology solutions. During each monthly meeting, a short 30 minute presentation about the state of current exchange technologies will be given. Individual Workgroup members suggested presentations from SAMHSA, the Indiana Exchange, the SHARPS program, and Intersystems.

Prior to the next meeting:

- The Workgroup was asked to identify areas of concern as well as other areas that may need additional measures. The Workgroup was asked to send comments to Mr. Handler, Mr. Eckart, or Mr. Rhodes.
- The foundational document entitled "Report of Preliminary Findings and Recommendations" would be distributed to the Workgroup and members.
- Members should send Ms. Heaney any personas that they believe to be relevant for the purposes of discussion by September 24th.

The Consent2Share discussion was postponed until next meeting.

Public Comment

There were no public comments.

Next Steps

The next meeting is scheduled for October 8th. Meeting minutes will be circulated in advance.

Adjournment

The meeting was adjourned at 3:23 PM

Minutes submitted by:

Daniel Procyk, Esq.